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## Rights advocacy through participation in policy implementation: the case of the French disability rights movement<sup>1</sup>

Working paper

### *Abstract*

Even though the study of disability rights advocacy has led to major contributions to social movement sociology and theory, the role played by the disability rights movement in the politics of implementation of disability policy within street-level bureaucracies remains largely unstudied. Based on a study of the disability sector in France, this paper explores this less-documented aspect of disability advocacy, focusing more specifically on the role played by association representatives in the allocation of disability rights. Indeed, following a major 2005 reform of disability policy, these representatives were granted a third of the seats in the local committees in charge of the allocation of disability rights on an individual basis. Mainly drawing on interviews with volunteers and professionals sitting on these local committees, as well as observations of committee meetings, this paper analyzes how movement members define their role in this institutional context. It first analyzes the role played by disability rights organizations in counseling disabled people and their families before they submit their applications to the local bureaucracy in charge of allocating disability rights (*Maisons départementales des personnes handicapées*, MDPH). The study of pre-application counseling practices reveals a clear partition between volunteers and professionals, as well as intra-movement differences regarding voluntary involvement in counseling. Being on the allocation committees, association members' interiorization of institutional constraints does not result in their assuming a purely institutional role, but favors a reframing of advocacy, in terms of oversight rather than participation in decision-making.

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## Introduction: advocacy through allocation?

The study of disability rights advocacy has led to significant contributions to social movement sociology and theory, be it through analyses regarding the conditions under which disability consciousness may arise (Groch 1994; Scotch 1988; Vanhala 2011), the impulse given by the disability rights movement in legal and policy change as well as in the more general transformation of common representations of disability (notably from a “biomedical” to a “social” vision) (Carey 2009; Erkulwater 2006; Fleischer and Zames 1998, 2011; Scotch 1984; Stone 1984; Switzer 2003), the uses of strategic litigation by the disability rights movement (Kelemen and Vanhala 2010; Mezey 1988; Vanhala 2011), or the role of social movements in “legal transplants” and the way the civil rights frame was imported from one country to the other by disability rights activists (Heyer 2002). Based on a study of the disability rights movement at the local level in France<sup>2</sup>, the aim of this paper is to shed light on a less studied aspect of disability rights advocacy, under the form of movement members’ participation in the allocation of disability rights in street-level bureaucracies.

Much less studied than advocacy at the stage of agenda-setting and policy definition, social movements’ role in the “politics of implementation” of disability policy (Percy 1989) so far has been studied from two different perspectives: the use of strategic litigation as a way to favor rights enforcement (Vanhala 2011), and the contracting of movement organizations by public authorities as service providers, in a logic of delegation of public service (Barral 2007; Heng-hao and Ming-sho 2008; Smith and Lipsky 1993a). While strategic litigation now is apprehended as a social movement strategy in its own right (McCann 1994, 2006), studies that focus on service-providing and the integration of SMOs as policy tools within the implementation process tend to stress the negative effect of this form of movement action on movement activism (Skocpol 2003). The effects of this form of movement institutionalization are analyzed in terms of de-radicalization or corporatism (Smith and Lipsky 1993b; Wilson 1988), contracting and serving as service-provider being described as favoring a weakening of activism (Heng-hao and Ming-sho 2008) as well as a reduced autonomy of organizations in defining the format of service provision in their own terms (Priestley 1999).

The equation of movement institutionalization with de-radicalization or the end of advocacy however has been questioned by other writings in social movement theory, notably based on studies of women’s movement activism (Banaszak 2010; Bereni and Revillard 2012; Katzenstein 1998). Advocacy, these authors argue, may redeploy itself within institutional settings, with sometimes more significant effects than street protest (Katzenstein 1998). This does not mean that institutionalization always preserves advocacy, but simply that no

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<sup>2</sup> The fieldwork at the basis of this paper was conducted as part of a broader research project on French disability policy at the local level, conducted by Pierre-Yves Baudot. Entitled “*Les MDPH, un guichet unique à entrées multiples*” (“MDPH: a one-stop shop with multiple entries”), this project was funded by MiRe-DREES /CNSA/ Conv. 10/4928 (Baudot et al. 2013). The research team included Pierre-Yves Baudot, Nicolas Duvoux, Aude Lejeune, Gwenaëlle Perrier and myself. Within this project, I was in charge of studying the role of disability rights organizations at the local level. I wish to thank my research teammates for all the discussions we had throughout this project, on the field and afterwards, which notably helped me grasp disability rights organization into their broader institutional context. A special thanks to Pierre-Yves Baudot for inviting me to join this project. I also wish to express my gratitude to Bernard Corminboeuf at OSC for his precious technical help in formatting my references database.

systematic assumption can be made regarding its effects, which need to be analyzed empirically.

This is what I offer to do here, focusing on the role of disability organizations in the implementation of disability policy at the local level in France. The more specific aspect I choose to focus on in this paper is the participation of these organizations in the allocation of disability rights. Indeed, following a major reform of disability law and policy in France in 2005<sup>3</sup>, “association”<sup>4</sup> representatives were granted a third of the seats in the local committees in charge of the allocation of disability rights on an individual basis, according to a participatory system of rights allocation that has become common in French social policy, described in social policy literature as “social magistratures” (Astier 2000; Bertrand, Caradec, and Eideliman 2011; Bureau and Rist 2013; Weller 2000). This takes place in the context of an increasing individualization of social policy, where disability rights are to be allocated on an individual basis, notably based on the applicant’s “life project” and on a multi-disciplinary expertise that, beyond the medical aspects, is to take into account the concrete effects of disability on daily life according to each person’s life situation (Astier and Duvoux 2006). This reflects a French model of disability which, since 2005, mingles aspects of the biomedical and the social vision of disability<sup>5</sup>. Such a context increases the autonomy of the local levels of government in rights enforcement. What has been classically described in political science as bureaucratic discretion (Dubois, 2010; Lipsky, 1980; Maynard-Moody & Musheno, 2003; Weller, 1999) is thus not only reinforced by these new institutional arrangements, but also transformed by them, given this unprecedented role allotted to civil society organizations in rights allocation. Civil society disability rights advocates therefore are put in a position to influence bureaucratic discretion in the implementation of rights. Based on interviews with representatives and direct observation of committee meetings, my aim is analyze how members of disability rights organizations have defined their advocacy role within these committees.

More precisely, within the framework of an analysis of social movements and rights enforcement, my aim is twofold. First, it is to document and analyze a particular type of movement institutionalization, to empirically seize the forms and consequences of movement entry into local institutions, without making any preliminary assumption regarding possible de-radicalizing or co-optation effects. Hence the very open question of “how do movement members define their roles in these committees”: is there unity or disunity among movement members? How do they intervene in the discussions on individual applications? How do they make sense of their participation, what meaning do they give to it and what aspects of institutional work, according to them, are important to invest? Working at the local level will enable a precise description of the type of relationship that unfolds between associations and public authorities, beyond the theoretical distinction between “movement” and “institutions”:

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<sup>3</sup> Loi n° 2005-102 du 11 février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées.

<sup>4</sup> “Associations” is the term commonly used in France to refer to non-governmental, non-profit organizations. It refers to a legal status, that of the 1901 law on association contract, that regulate these organizations.

<sup>5</sup> In parallel, in a similar way as what took place in Germany (Heyer 2002), a civil rights frame is gradually being introduced within the old social welfare model of disability policy, notably through a growing reference to discriminations, as well as the defense of rights such as school integration and accessibility (Chauvière 2003).

what happens when social movements get inside institutions? What do movement members concretely do and how do they make sense of what they are doing? To what extent do social movements submit to or interiorize institutional norms and constraints, and should this socialization be interpreted in terms of institutional domination or movement strategy? And finally, how does their role in service-provision influence movement organizations' definitions and forms of advocacy within institutions? Secondly, my aim is to deepen the understanding of what "*rights advocacy*" means in the field of disability. How are disability rights, rights whose definition often remains "vague" in the law<sup>6</sup>, defined throughout participation in these local committees, and what types of action does rights advocacy concretely translate into? While disruptive practices such as street protest remain the most analyzed forms of rights advocacy<sup>7</sup>, what can be said of what happens at the more discreet level of street-level bureaucratic right allocation? Does rights advocacy mean allocating rights in the way that suits the best the applicant's need and entitlement, or does it mean taking into account the local chances of rights-effectiveness in the very definition of the rights being allocated? Does it mean having a say on each individual file or defining a procedure of scrutiny and control over decisions taken by the local authorities? How does participation in the committee combine with the possible counseling provided to applicants before they submit their applications?

These are some of the questions I will be addressing based on ethnography of the French disability rights movement conducted at the local level (that of the French "departments" or *départements*, the intermediate level of government between municipalities and regions). I will first give an overview of the French disability rights movement and the main changes introduced by the 2005 disability law, before getting to the movement's role in the definition and allocation of rights at the local level, through applicants counseling and through association members' participation in the local committees in charge of rights allocation.

### **From service-provision to advocacy...to rights allocation: the French disability right movement, grasped from the local level**

The role disability organizations have come to play in the allocation of disability-related rights in France cannot be understood short of a consideration of the history of this movement and its role in the development of disability policy. Impairment-specific disability organizations, as of the aftermath of the First World War, are the ones which created the first facilities and services for disabled people, before the state got involved (Azéma 1999). And when the state started intervening, contracting with associations to fund the existing facilities

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<sup>6</sup> As A. Carey reminds us: "Even when a law substantiates a right, the right does not exist as a neat guarantee. An individual must claim the right, and then that claim is negotiated within the contexts of micro-relationships and macro-social institutions, possibly including the legal system, where concerns are expressed, costs are weighed, and conflicts are mediated. Disability law is vague precisely to allow this negotiation to occur" (Carey 2009:214).

<sup>7</sup> For example, Barnartt and Scotch identify 14 types of tactics used within disability protest: march, demonstration or rally, takeover or lockout, sit-in or refusing to leave, chaining themselves to something, meeting with or lobbying someone, interrupting, booing, jeering, blowing whistles or making noise, vigil, candlelight or other, wearing or displaying relevant information, chanting, handing out information, strike (hunger, rent or other) or boycott, blocking anything, crawling, demanding something (Barnartt and Scotch 2001:83).

and services was a main form of intervention. Public authorities did not create their own public network of facilities and services, but relied on the existing ones managed by associations<sup>8</sup>, in a process similar to what was documented in other sectors of social policy in France (Lafore 2010). While disability organizations therefore play a structuring role in this public policy sector, state intervention reciprocally shaped the movement, first and foremost by defining “disability” as a public policy sector as of the main structuring 1975 law, which led to the creation of links between impairment specific organizations which initially had very few ties with each other (Paterson et al. 2000; Stiker 2009). Even though some more “anti-establishment” movements, notably student-based, developed in the 1970s (Barral 2007; Ville 2008:132–133), the sector, even in this period, remained dominated by large, reform-oriented organizations that maintain a close relationship with public authorities at different levels of government. As Barral stresses “Combining the roles of founders, administrators, employers and beneficiaries of the institutions, associations manage 80% of the equipment, a virtual monopoly that sanctions their partnership with the government” (Barral 2007:220). This does not prevent the same organizations from adopting more confrontational repertoires of action when deemed needed. For example, a regrouping of associations called “*ni pauvre ni soumis*”<sup>9</sup> (“neither poor nor submissive”, a name which mimics the feminist organization “Neither whores nor submissive” – “*Ni putes ni soumises*”) was created in 2007 to demand an increase in the amount of the adult disability benefit (AAH). They organized a major national street demonstration in Paris on March, 29<sup>th</sup>, 2008, after several other demonstrations took place at the local level in the two previous months. Therefore, the same organizations may combine discreet lobbying tactics with more confrontational actions. Inter-organizational networks reflect this status both inside and outside institutions, with two parallel groups of different statuses: indeed, about the same organizations are represented both within a state-initiated advisory council, the *Conseil national consultative des personnes handicapées* (CNCPH), and within a more autonomous organization (*Comité d’entente*, joint committee) dating back from the ties between associations that were established during the preparation of the 1975 law (“Groupe des 21”).

My aim here is to grasp this complex reality of the contemporary disability rights movement in France by looking at a very particular aspect of the actions of these associations which takes place at the local level, which is their participation in the allocation of disability rights. This new role granted to disability organizations follows changes introduced by the major disability policy reform that took place in France in 2005.

The 2005 law created a single administrative body in charge of the implementation of disability policy at the local level, the *Maisons départementales des personnes handicapées* (MDPH). Within this institution, individual applications are processed by administrative teams, but the final decisions are taken by a committee whose 21 members include 7 representatives of associations. This “disabled persons’ rights and autonomy committee” (*Commission des droits et de l’autonomie des personnes handicapées*, or CDAPH) is the final

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<sup>8</sup> Disability institutions received public funding as of 1956 (Barral 2007).

<sup>9</sup> Ni pauvres ni soumis, « Naissance du mouvement Ni pauvre, ni soumis », [http://www.nipauvrenisoumis.org/f\\_histoire/](http://www.nipauvrenisoumis.org/f_histoire/)

decision-maker regarding the allocation of all forms of disability related rights, as well as the definition of applicant's entitlement to specialized institutions or services. For example, this committee makes the final decision regarding what type of school a disabled child can apply to (mainstream school, in some case with a certain number of hours of individual or shared human help – the number of hours being also defined by the CDAPH, or specialized “medical-educational” institutions (*institut medico-éducatif*, IME)). The committee also decides whether an applicant may be recognized as a disabled worker, which opens entitlement to workplace accommodations (*Reconnaissance de la qualité de travailleur handicapé*, RQTH), as well as whether the applicant may receive disability benefits (Adult disability benefit (*Allocation d'adulte handicapé*, AAH), or Child disability benefit (*Allocation d'éducation de l'enfant handicapé*, AEEH)). Among many other competences, the CDAPH is also in charge of defining entitlement to and the amount of a new benefit created in 2005 in order to cover part of the special costs linked to disability, the disability compensation benefit (*Prestation de compensation du handicap*, PCH): this benefit can be used for example to pay for a wheelchair or other type of technical equipment, for home improvement costs (when work is needed to make the home accessible), or for a home helper.

The fieldwork at the basis of this paper was conducted as part of a broader collective research project on French disability policy at the local level (Baudot 2013). The project included the study of the local authorities in charge of disability rights allocation at the local level, the *Maisons départementales des personnes handicapées*, or MDPH, in four departments. Our team spent about a week doing fieldwork in each department, each of us specializing in a particular aspect of the MDPH's inner workings and environment (users, litigation, and civil society organizations). I studied the role of disability rights organizations, with a priority focus on the organizations which are represented in the MDPH's “rights and autonomy committee” which is formally in charge of allocating disability rights. These organizations often are the same from one department to the other, and belong to national federations of associations which are the most prominent voices of the movement at the national level (mainly APF, UNAPEI, UNAFAM, APAJH, PEP, AFM). Most of them manage facilities and services, and their boards are mainly composed of parents and “close relatives” of people with disabilities, as opposed to the latter themselves (they are organizations “for”, rather than “of” disabled people (Vanhala 2011:156)). Exceptions notably include two mobility-impairment organizations, the *Association des paralyses de France* (APF) and the *Association française contre les myopathies* (AFM), as well as several associations (which often differ from one department to the other) in the field of hearing and visual impairments which encourage the participation of people with disabilities. The study was primarily based upon semi-structured interviews with association volunteers (N=33) and facility and service managers (N=13). The interviews almost all took place on the premises of the different associations, facilities and services, which gave me occasions of direct observation. The interview transcripts were coded using *Atlas.Ti*. I also observed four sessions of “rights and autonomy committees” in three different departments.

Representing one third of the committee members, associations are in a position to actually have a say in the allocation of rights at the local level, even though they do not have decision-

making power as such, being a minority. However, their influence on the way rights are defined and implemented at the local level also rests on other aspects notably linked to their management of almost all of the facilities and services in the disability sector. Hence, before the commission, they play a part in the preparation of individual applications, as well as, to some extent, in their evaluation within the MDPH. And after the commission, the facilities and services managed by the associations are the ones that have the ultimate power to make some of the rights allocated a reality. This involvement around the committee will be analyzed first, before turning to the way disability organizations make sense of their presence in the committee as such.

## **The role of third sector disability organizations in the preparation and evaluation of individual applications**

The role of civil society organizations in access to rights having been documented in other sectors in France (Lejeune 2011), and in an analogy with the prominent role of social movements in accompanying individual right claims in front of the Courts (Manfredi 2004; McCann 1994, 2006; Vanhala 2011), one of the aims of the investigation was to assess the extent of support provided by associations in the preparation of individual applications. It soon appeared that two very different aspects of the organizations' role had to be distinguished in this respect. Indeed, associations do not only play a role as voluntary organizations (and as such, their part seems rather limited), but they also manage facilities and services whose professionals almost systematically take part in application renewals for their registered users.

### **Volunteers' limited role**

Many voluntary board members note applicants' lack of knowledge of their rights, stressing the fact that they would need more information in order to actually have access to the full range of rights they are entitled to. As the board member of an organization mainly advocating for mobility-impaired people, who also sits at a CDAPH, stresses:

*I don't know whether people are really aware of their rights. I mean, of exactly what they are entitled to, because their rights, they might say "I may be entitled to disability compensation benefit", but I mean, in terms of the number of hours of home helper [that will be paid for by the benefit], I think a lot of people easily accept what they are offered. [...] There are people who do not belong to associations, and we come to think that these people, they get - not "had" - but they are offered this and they accept it, and that's it, but maybe they could have more.*

However, this general diagnosis regarding the lack of legal information does not translate into the institutionalization of permanent legal information services within civil society organizations, apart from a few exceptions such as the FNATH, which notably specializes in litigation following workplace injuries (Lejeune and Revillard 2012), and the AFM, which is close to the field of other patient's rights organizations. In most other organizations, there is no permanent voluntary service in charge of helping applicants. People asking for advice regarding their applications generally are redirected to the social services of the MDPH.



While this reflects a refusal to help applicants directly, this redirection may be of some help to the applicant compared to a direct contact with the MDPH, in so far as associations sometimes direct applicant to very specific people within the institution, who specialize in the kind of issues they are dealing with (schooling, employment, etc.). For example, this excerpt by two interviewees who volunteer for a psychic disability association, while revealing that not many people come to the association for this type of advice (5 in a given year), illustrates how specific contacts can be given to such people:

*Q: Before the CDAPH, do some people come and ask you at the association for advice on how to file their applications?*

*A1: Not very often. Some people do, but not systematically. [turning to another volunteer] Did many people come and ask us for advice on how to file their MDPH applications?*

*A2: We have 5 requests of this kind per year. And we delegate a lot. Sometimes I give them - they call us to ask for information, I give them an appointment, but we don't fill in the document for them. We hand over to – if it is child-related, to the person in charge of the childhood department [at the MDPH]; and if it is an adult, if it is work-related, Mrs X [person in charge of the department at the MDPH]; if it is for an institution... we hand over to the MDPH.*

Therefore, even though some volunteers within associations may offer their help upon request on an individual level, there is a shared assumption, among most associations, that counseling regarding application filing is the MDPH's job.

*And what I am saying is that the MDPH are not doing their job properly because people don't know their rights. [...] To be sure, when clients come in and their files are incomplete, they will ask for complements: "I need the medical record, this is missing, you should bring in photos...". This, they will say. But all the counseling that should go along, this is not done.*

Refusal to institutionalize this type of counseling within the voluntary sector partly corresponds to a will to exert pressure on the MDPH in order to avoid attempts to delegate what is considered a public service to the third-sector. But it also derives from the lack of time and volunteers for this type of work. Finally, it reflects a reluctance, on the part of some association leaders (predominantly middle to upper middle-class retired white males, often members of the local notability) to assume a role that is assimilated to a form a "dirty work" (Hughes 1958) provided by social workers (*assistantes sociales*, a predominantly female activity in France) as opposed to the more noble, "political" tasks of "representation" that they conceive as the core of their mission as board members. This appears quite literally in the following quote by a board president who, after describing the volunteers' role in helping people identify the right contact within the MDPH, stresses that their involvement does not include a more active help in application filing because "we are not social workers":

*Q: So you will not necessarily be providing a more active help on the details of the application? Like, helping people file their applications or things like that?*

*A: No. Not necessarily, no. I try to avoid it. There are people whose job it is. I mean, we are not social workers. I try not to play that game. I do have a role in informing, helping*

*families in need, we must help them. But no, we are not social workers. Each of us must stay in their own place. [...] Some time ago, I was in [a different chapter of the association] where the president, his wife was a social worker. She received the families in her own home. [After work] she came back to work on the applications from home. No. I already spend 33 hours per week [for the association], that is already some time.*

This last reference to the counter-example of the wife of the president of another chapter of the association who was a social worker and provided applicants with this type of help well illustrates the gender and “dirty work” dimensions of presidents’ reluctance to assume this role. This, as well as the idea of “helping people in need”, also reveals the fact that counseling people regarding their applications is read in terms of charity, or at the most, in terms of traditional social work, and not in terms of empowerment and facilitating access to rights. To be sure, this vision is not systematically shared among associations, but the simple fact that most association leaders are not too keen on institutionalizing this mission in their structures reflects the fact that it not given much political meaning. It is seen as “help”, rather than empowerment. Beyond the fact that most associations do not provide permanent structures for this type of counseling, this also translated into associations’ refusal to offer this type of counseling on a voluntary basis within the MDPH, when asked to do so. In one of the departments studied, the associations collectively refused, and in another, only 2 associations accepted.

However, as suggested earlier, some volunteers do accept to provide advice on an individual basis, even though this type of service is not institutionalized within the structure. Such is for example the case of a volunteer whose association refused to have office hours devoted to counseling at the MDPH, but who receives applicants up until late at night at her home in order to help them with their applications:

*They [the association leaders] believe that the associations should not replace institutions, that the institutional people... [should be doing the job]. But I believe that if we keep kicking the ball back and forth to each other, we are never going to get out of this.*

Based on the four departments studied, I have found provision of administrative counseling to applicants to be more common in associations in which the volunteers/board members are themselves disabled people: in France, this is mainly the case of some associations specializing in mobility-impairment as well as visual and hearing impairments. Examples of the types of advice provided include “not making useless claims” (E27) (claims that have no chance to succeed, implicitly because it tends to annoy MDPH people), help in the writing of the applicant’s “life project”, advice on the mentions and details that are needed in the medical certificates, and possibly on the local doctors who best know how to fill these in. This quote by a volunteer in the field of visual impairment reflects how useful this type of knowledge regarding the local practitioners might be:

*Q: What kinds of things will you typically be giving people advice about?*

*A: I mainly advise people regarding the medical certificate. I explain them what they must ask their doctor for, what the doctor must write down. [...] The thing is, I am under the impression that there are – well, true enough, doctors are overbooked – but doctors*

*tend to be casual regarding the certificates they must fill in. In fact, there is a very clear difference, even between eye doctors, when you look at how they fill in the certificate. It is clear. Very clear. Here, there are two of them who fill in the certificates very well, with the pictures and all, everything that is needed, but the others...*

In other cases, the involvement of associations in pre-application counseling may take on a more political meaning, being part of a struggle to improve disability rights by promoting in some cases a broad implementation, which would go beyond legal prescriptions. Such is particularly the case of the *Association des paralysés de France* (APF), one of the main associations that struggle for the improvement of disability rights (its constituency being mainly based on mobility impairment) at the national level. In the following excerpt, the head of a local chapter of the association insists on the usefulness of associative counseling in order to tell people about the “tricks” beyond the “administrative answer”, and tells us about an individual case on which their “social worker<sup>10</sup>” is currently working, which involves trying to get entitlement to disability benefit to an applicant in spite of his spousal situation putting him out of the legal range of entitlement:

*Q: Before the CDAPH, do you have many members asking you for advice on how to write or build their applications?*

*A : Yes, we have a lot of requests, because the MDPH remains... So, there was this will to create a one-stop shop [when the MDPH was created], which is already something. But still there is, for writing the application or the life project – this is why we have hired a voluntary social worker, in fact – that is, in preparing for the application, we can offer counseling. Because people do not necessarily know, even if they ask the MDPH. An administrative answer is what they will get. They do not know all the tricks, what can be accepted, what cannot be accepted, where you can... That's it. And then, [...] we have this case, the social worker is currently working on a really blatant case, it is a household with two kids. He is with disability, she works for the minimum wage. He doesn't get the AAH [disability benefit] because she is on the minimum wage. So we are fighting so that he however gets part of the benefit [...].*

Even though this interviewee does not comment on it, this attempt, at the local level, to get disability benefit to an applicant who legally is not eligible due to his spouse's income, mirrors the association's current fight, at the national level, to legally disconnect individual benefit entitlement from the spouse's income<sup>11</sup>.

However, this type of attempt to use applications in order to improve rights allocation practices beyond what is legally prescribed (with the hope to eventually favor legal change and enshrine new rights in the law, in a manner similar to strategic constitutional litigation) is generally rare. The main conclusion remains the weakness of legal/administrative service provision at the level of voluntary organizations.

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<sup>10</sup> This local chapter of the association indeed has “hired” a voluntary social worker - an exception to the general conclusion we have drawn earlier

<sup>11</sup> In a classic process of frame extension, in the context of the French debate on same-sex marriage, the APF issued a press release entitled “Marriage for all except for disability benefits recipients” (“marriage for all” was the motto of same-sex marriage advocates): APF, “Le mariage pour tous sauf pour les bénéficiaires de l'allocation adulte handicapé”, *Faire face* (APF blog), 12/02/2013 <http://www.faire-face.fr/archive/2013/02/06/le-mariage-pour-tous-sauf-pour-les-beneficiaires-de-l-alloca.html> (Snow et al. 1986)

## Facility and service managers' systematic involvement

Volunteers are far from being the only actors involved in associations in the field of disability, since many of these associations also manage highly professionalized institutions and services, which hire personnel mainly within social care, educational and health occupations : these include “medical-educational” institutions (*institut medico-éducatif*, IME), sheltered employment facilities and services (*Etablissements et services d'aide par le travail*, ESAT), medical care/nursing homes (*Foyers d'accueil médicalisé*, FAM/*Maisons d'accueil spécialisé*, MAS), social support services (services d'accompagnement à la vie sociale, SAVS).

These institutions play a significant role in counseling their users regarding their MDPH applications. Indeed, applications for disability rights (be they benefits, disability compensation, or assignment to a given institution or service) must be renewed on a regular basis; therefore being accepted in a given service or facility does not mean the end of administrative procedures for applicants. However, the main difference for them is that once they come under a given service or institution, their MDPH applications are generally closely supervised by the latter. Indeed, unlike what was described earlier in the voluntary side of associations, the function of user counseling regarding MDPH applications is quite systematically institutionalized within the services and institutions managed by the associations : depending on their size, these generally include a person specifically in charge of this mission, and in some cases a whole “social service”.

This involvement in users counseling does not only or even necessarily derive from a commitment to disability rights advocacy, but also mainly from the fact that the outcomes of users' applications are decisive in defining the services' public, and the characteristics and behavior of their public is perceived as the main source of uncertainty by facility and service managers, an uncertainty which they will logically try to reduce (Crozier and Friedberg 1977). Indeed, these publicly-funded institutions and services cannot – and do not – “recruit” a user without a CDAPH notification; they cannot legally put an end to the management/care of a patient without a CDAPH notification either, even though compliance with the procedure seems less systematic at this end of the process (a few cases of users being fired from sheltered employment (ESAT) without or in spite of CDAPH notification have been reported). This means that the profile of the institutions' public (who gets in and who gets out) can only be defined within the borders of the MDPH's decisions. Institutions however generally keep a significant margin of autonomy within this perimeter, given the situation of the market in the field of disability facilities and services: indeed, institutions have an obligation to follow-up on CDAPH's decisions provided that they still have vacancy. In other terms, if the CDAPH notifies a certain type of facility or service for a person, this facility or service must accept this user *provided they still have available room*. For most services, demand is largely higher than supply; hence the institutions keep a margin of autonomy, being completely autonomous in the management of their waiting list (the MDPH has no power to impose priority of access or to define a rule for managing the waiting list, such as “first come, first served”). However, it still matters, for institutions, to be able to control to some extent the notifications that are made by the MDPH, and they also need to avoid the situation in

which their users would find themselves – and put the institution – in a difficult position due to failure to renew their applications. Hence, apart from their possible commitment to disability rights advocacy, it is in the interest of disability institutions managers to ensure that their users are up to date in their administrative procedures, and possibly, as will be shown below, to try to influence decisions regarding new users by taking a part in the evaluation process within the MDPH. In one case, the MDPH even appears to have encouraged a service to provide such counseling, according to a medical-educational institution manager:

*The MDPH appointed social workers to help with writing up the applications. Except that they found at it worked more or less, and they asked us to help the families. In the beginning, we helped those who came, and then we decided to work on all the applications, and in fact, the applications are filed from the institution, in relation with the family of course. For us, it is also a guarantee [...] not to find ourselves with nothing at the end of the period of time initially notified by the MDPH.*

Indeed, all the service managers I have met argue that their recommendations regarding people they have helped are almost systematically followed by the MDPH. For example, these two managers in charge of several sheltered employment institutions mention only one case, during the course of a year, in which the MDPH did not follow the institution's demand:

*Q: Concretely, does the MDPH follow you?... If you work on 90% of the applications [of the disabled workers who work in your facilities] before they are submitted [...], does the CDAPH generally follow you, afterwards?*

*A1: Yes.*

*A2: Always. If you take, for example, last year, I think that the only request that was not validated – and it is understandable – is a request for an exit<sup>12</sup> from an establishment because we were faced with very, very high absenteeism on the part of the disabled worker. We had had a whole procedure with the MDPH, we had referred to them on several occasions, and finally, we decided to request an exit from the establishment, and they – how should I put it? – refused it, because for them, even though the absences were numerous, this was, for this person, the only remaining social link. We understood it. For us, it seemed consistent to ask for it, but we accepted [the decision] and at the same time, we committed to follow-up with them on the person's absences. Generally speaking, they follow us.*

Significantly, the case in point was a case of “exit” from an establishment, a case which illustrates how management logics (here, the aim to avoid too many absences on the part of a disabled worker) may interfere with the defense of disabled workers' rights (a defense which translates here into the CDAPH's defense of a right for the worker to remain in the institution in spite of his numerous absences, in the name of the preservation of his social integration).

The general success of the recommendations made by the managers of institutions and services (apart from such – significant – exceptions) largely derives from their close knowledge of the users (who are present in their services on a day-to-day basis) and the administrative procedures, as well as the role they actually come to play in the evaluation

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<sup>12</sup> « Exit of establishment » (sortie d'établissement) concretely means here that the sheltered employment institution wishes to lay off a worker.

process. Indeed the MDPH relies a lot on the expertise of the institutions, by means of different channels: the technical teams in charge of the evaluation of individual applications within the MDPH may ask the local institutions and services for advice regarding the possible appointment of users, and even ask them to accept an applicant for a short period in order to “test” the relevance of a given appointment; professionals from the institutions may also sit on the evaluation boards of the MDPH (the multidisciplinary boards that proceed to the evaluation of individual applications and present the CDAPH with a decision proposal, before the final decision is made by the CDAPH); finally, and especially in departments where there is a lack of medical specialists, specialized medical practitioners (such as psychiatrists) may work part-time for the MDPH and for different institutions.

To sum up, the involvement of facility and service managers in application renewals is more systematic and institutionalized than the counseling of (generally first-time) applicants by the volunteers of the organizations that often own these facilities and services. This participation in the application process, which mainly derives from a management logic (controlling who gets in and who gets out, in order to control to some extent the public’s profile), can easily be understood drawing on organizational theory rather than social movement theory. In other terms, the same action (helping someone with their disability rights application) that we initially envisioned as part of a social movement tactic to promote rights enforcement, actually may take on a very different meaning when performed by professionals in an institutional context. This raises important questions regarding the frontiers and definition of advocacy: to what extent can advocacy be substantially defined by the actors or the actions involved? If not, must one take into account the effects (effectiveness of the rights for the applicants, capacity to enforce rights beyond what is legally prescribed...) or the intention, the meaning conveyed to the action by the actors (advocacy or professional management of a population)? Beyond this particular case of disability advocacy, this case study sheds light on structural ambivalences of institutional advocacy that we have previously analyzed in other contexts, the promotion of human rights by the French Ombudsman (Revillard 2010; Revillard et al. 2011), and the definition of gender equality policy by women’s rights advocates within the state (Bereni and Revillard 2011, 2012; Revillard 2007). As we will see, these ambivalences linked to advocating in a bureaucratic context also unfold at the level of participation in the CDAPH.

### **Defining a form of rights advocacy adjusted to institutional constraints: associations in the rights and autonomy committees**

Before analyzing the participation of association volunteers in the rights and autonomy committees of the MDPH, it is important to stress, in relation with the previous section, that service and institutions managers also play a role at this stage. As such, “representatives of organizations that manage services and institutions” are legally granted two advisory seats on the committee (they don’t have the right to vote). But beyond this, in practice, some associations also send their managers or members of the professional staff of their services

and establishments to sit as representatives of the association<sup>13</sup>. Therefore, the influence of local facilities and services does not end at the door of the CDAPH.

Turning to association representatives more generally speaking, this section aims at analyzing the forms taken by advocacy in this particular context which is both strongly institutionalized, and where the main official logic of action is the allocation of rights on an individual basis. This formal definition of the CDAPH's mission first invites us to look at the way association representatives advocate for disability rights during the discussions on individual applications. But the direct observation of the actual functioning of the committee, as well as the interviews with association representatives, also lead us to shift the focus of analysis – as these civil society organizations themselves have shifted their focus of advocacy – from the involvement in the defense of each individual case to a mobilization aiming at the norms of functioning of the committee. Indeed, because of constraints tied to the number of individual files to process and the limited time spent in committee (constraints that are largely integrated by association members themselves), only a small part of the applications that are submitted to the MDPH are actually presented in front of and discussed by the CDAPH. In this context, disability rights advocacy tends to take the form of the defense of a right of oversight on MDPH decisions, making the MDPH accountable, rather than actually participating in the decision-making process on each individual application.

### **Speed-advocacy? The defense of disability rights within a quick decision-making process**

Given the time constraints of the CDAPH, associations representatives, when they intervene, have to make their point rather quickly (even though the time devoted to each individual case being discussed varies a lot from one department to the other, for example in one of the department studied an average of 6 minutes was spent on each application). Although association volunteer leaders as well as institutional actors in the field of disability tend to theorize a sharp distinction between the “activist” or “political” stance of the volunteers and the “technical” or “expert” point of view of the service and institution managers, both the observation of the nature of the interactions within the CDAPH and the volunteer leader's accounts of their participation in the commission show that expertise is the dominant mode of intervention, including on the part of “activists”. In the semi-structured interviews, when I ask volunteer association leaders about why participating in CDAPH meetings matters for them, in the answers the shift from the lexical field of rights to that of expertise is very common:

*Q: According to you, what does it bring to be present at the CDAPH? What is the interest for associations to be present in this type of instance?*

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<sup>13</sup> The question of who should sit as “association representative” (whether it should only be volunteers or also professionals) is not settled by law, so it varies according to the local practices of both the different associations and the MDPH. For example, the APF decided as a national policy of the association that board members, generally people themselves with disabilities, should be the ones serving on CDAPHs. In one of the departments we studied, the MDPH director recommended that associations be represented by volunteers rather than by professionals, in order to have an “activist point of view” represented within the committee, rather than a “technical” one (that is assumed to be that of the managers/professionals).

*A: The interest is the defense of people with disabilities. Well, I do not mean that they would not be well defended otherwise. If we weren't here, maybe it would work the same way, this is something we cannot say. But, well, we do see that on the applications we intervene on, we do bring in our knowledge, because not everybody is necessarily aware of everything, and it helps a lot.*

Another volunteer president, belonging to a local deaf people organization, argues that associations bring in a specific expertise to the MDPH:

*Within the CDAPH, I think association representatives have brought in skills that were specific to them. Let me give you an example. MDPH technicians, in general, knew very little about deafness. So regarding certain questions, they did not know how to proceed. The [MDPH] director had organized a meeting with us, with associations in the field of deafness, to say: "Here we are, on these issues, what is your opinion? How will we proceed?". At some point it was about hearing aids, and all. Because it's true that since it is very specific, there were not many technicians, indeed, that mastered the subject.*

Facing what they describe as a lack of knowledge of the issues by MDPH technicians or other representatives in the CDAPH, association members put forward an expertise based on their experience of or closeness to the disability being discussed, when representatives are themselves disabled people, parents of disabled people, or can put forward their closeness to the disability at hand they have acquired through their voluntary work. In doing so, they may encounter difficulties when put in a position to discuss the medical diagnosis and assessment of the level of the bodily or mental dysfunctions (which partly conditions access to some of the benefits), because of the superior legitimacy of medical knowledge and because of the very partial access they get to elements of the medical record (due both to a reluctance of MDPH medical practitioners who put forward medical confidentiality, and to the limited time spent on each application during the CDAPH). However, their contribution often turns out more efficient, and is perceived as more legitimate<sup>14</sup>, when it is based on a description of the experience of disability in daily life, the concrete obstacles the applicant may face in terms of mobility and autonomy, and consequently the amount of support/compensation needed. This input proves all the more important in the context of the 2005 law which promotes a more social definition of disability than what was previously commonly used in France, and defines a "rights to compensation" by means of the PCH. Association representatives therefore often put forward these arguments in the context of discussions of PCH applications. For example, this president of an association in the field of visual impairment, who himself is blind, demonstrates the consequences of partial visual impairment on daily life in order to argue in favor of a better compensation of the disability, a situation which he compares with that of total blindness, which opens access to a fixed rate of PCH (*forfait cécité*) and is therefore relatively more easily to compensate for within the framework of the current administrative procedures:

*When you can't see well, it's hard. [For example if] you have retinitis pigmentosa: well, when there is too much light, you cannot see; when you go from light to the shade, you cannot see either. How do people move from one place to the other? How do people*

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<sup>14</sup> Given the small number of CDAPH directly observed (4), my analysis here is mainly based, at this stage, on interviews with association representatives, and should be considered as a very preliminary finding.



*communicate? If you go to a train station, nothing is accessible to the visually impaired. For someone who is visually impaired, when you see the height at which they put the timetables: nothing [you can see nothing]. You wait 20 minutes<sup>15</sup>, you're going to hear the voice, and then you still need to know where you are [in order to be able to locate your train]. We, when one is blind, there is no problem, we have the blindness standard rate (forfait cécité); and I am lucky enough to have colleagues who come and pick me up, my wife and all, but not everybody is as lucky as I am. Some people live alone, and how do they move from one place to the other, to go somewhere? Nothing is adapted. Everything goes through the eye in today's society. 95% of information goes through the eye. We, we only have left the senses of touch, smell and hearing. And we must compensate, with these three senses, for 95% of what a seeing person has. [Addressing me] You turn your head, you take a look, you immediately see what is displayed. Us, we need to ask, we need to find someone. But this, this is ground experience. In CDAPH, I explain this to them. And then they tell me: "This is very technical". I say: "Yes, but it is the ground reality".*

The expertise put forward by association members in CDAPH may also take the form of indeed very technical aspects, typically regarding different types of equipment: why such an expensive wheelchair is needed based on the person's impairment, how such hearing aid will help the applicant in their daily life, etc.

Given that expertise is public administration's constitutive language (Nass 1986; Weber 2003), this position of associations as purveyors of expertise within the CDAPH is strategic on a double level: in view of the applicant's interest (for it is likely to increase the chances of success of the claim), and in view of the association's credibility facing administrative actors<sup>16</sup>.

However, it is not the only possible one. Association representatives also intervene based on a defense of fundamental principles and rights. For example, in the following excerpt, a volunteer belonging to an association in the field of mobility impairment, himself in a wheelchair, recalls his intervention on a case discussed by the committee, where a disabled man, who could not use his arms and had full-time human help at home, was asking for financial compensation for the purchase of an automated garage door with a piece of equipment that would enable him to open the door by himself (using his mouth). Other members of the CDAPH argued against the allocation of the compensation benefit for this use based on the fact that he had full-time human help and therefore "the lady" [the helper] could open the garage door if needed. Against this stand, this representative argued that compensation was legitimate on the basis of a defense of the disabled person's autonomy:

*[...] There was this man who needed an automated garage door, indeed, because he didn't have his arms; he pressed with his mouth. But, there was always someone with him, at his place. So we heard: "But why does he want a door at such a price when there is someone at his place?". So, that is what I explained: the man, even if there is someone at his place, what if he wants to do things on his own?*

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<sup>15</sup> Trains in France are supposed to be announced 20 minutes before departure

<sup>16</sup> This strategic use of expertise by rights advocates within the administration, in terms of both legitimacy and efficiency, has also been documented regarding women's rights (Banaszak 2010; Katzenstein 1998; Revillard 2009)

*Q: It's a matter of autonomy.*

*A : It's a matter of autonomy. And [our organization], we promote this. And then I was told [by other members of the commission] : "No, I don't see why... There is someone at his place. The lady, she can come and open...". I said: "No, this is not what we want. Just because someone is there doesn't mean that the lady, she comes open the door. So that's it. In each case when there is someone at home [they say]: "The lady, she'll do it". No. We already have to bear with our impairment, so if on top of that we cannot do things by ourselves a little... [But that's the idea:] We won't pay for a garage door because someone else can take care of it".*

Here, the ideas put forward by the organization at the national level ("we promote this") find a direct illustration in the defense of an individual case, and the defense of autonomy may seem all the more legitimate since it takes place within a "rights and autonomy" committee. The defense of principles is put forward against the consideration of cost, which, notably regarding a piece of equipment that is deemed unnecessary (an automated garage door as opposed to a wheelchair for example), along with the idea according to which "the lady can do it", is what is at the root of the other members' opposition.

In other cases, association members may intervene (they are, however, not the only ones to do so) on the basis of a stress put on human situations in order to allocate rights even though the legal conditions are not strictly respected, as opposed to a more rigid application of the texts. For example, the same representative recalls the case of a person who, when his case was discussed by the CDAPH, was just about to get out of the hospital within 8 days and needed a wheelchair. His claim to disability compensation benefit to pay for his wheelchair had been rejected by the MDPH technical team because the applicant had only provided the MDPH with one estimate, as opposed to the two estimates that are officially required. Mobilizing his technical expertise, the interviewee stresses the fact that only one provider exists in France for this type of wheelchair. But he also condemns what he describes as a too rigid implementation of the "2 estimates" rule by MDPH members, which in this case leads to an applicant having to stay in bed:

*[...] often, what I am saying is... these doctors around the table, sometimes, they are a little tough, because if they were in the situation of the people [whose applications they are discussing], I think they wouldn't think the same way. I mean, it's my opinion. [...] It is a good thing that we are here because we can explain. Because when they refuse a wheelchair, me, I say, "sometimes, you refuse that, ok, because you think it is expensive". For example, there was a person who was about to come out of the hospital 8 days later, they refused the wheelchair. I asked them: "now explain me how the person is going to do". I mean, there are some MDPH where they are more flexible. But here, they are pretty much into the legal stuff. They won't deviate even one tiny bit. But then, you know, the applicants, they are in trouble. [...] Sometimes they say: "No, it can't make it because it is too expensive, because we need 2 estimates". [...] In this particular case, there was only one estimate because only one provider sells this type of wheelchair. And yet they wouldn't accept it. There was a vote by show of hands, and we lost, because we were two voices short; and then I said : "So explain this to me : this man who is going to go out of the hospital, he is going to stay at home laying down because he won't have a wheelchair. Now you explain this to me".*

Q : ok, so in this case, they say : “go and get a second estimate and come back to us”?

A: *That’s it. Sometimes I even get mad, even though I remain polite, but I really get upset; and they say: “There’s no use in getting so upset”. But sometimes, when you see some of the things... Within the CDAPH, it’s complicated. You need to be able to defend yourself. Because it’s tough. Even the doctors who are around the table. The time she [the doctor who had assessed the case] refused the wheelchair, in my head, I told myself : “You’d better not get unlucky one day because...”. I mean, when people are affected, you see the difference. But then, what I am saying is, when we are in the CDAPH, it is the law, pure and simple. That’s the way I see it. That’s the way I feel it. And the doctor always goes: “yes, but the [evaluation] grid doesn’t say that”. Well, yeah, maybe the grid doesn’t say, but there you go.*

Even though these two excerpts illustrate classical advocacy stands, in which the user’s right are promoted over any other (procedural, financial) consideration, association representative’s positioning often is more complex. Indeed, even reasoning within a logic of advocacy, because their action unfolds at the local level and because they are generally aware of the limited locally available means (all the more so since they manage services and institutions themselves), associations representatives often find themselves confronted with dilemmas regarding the best way to define the allocation of rights in order for these rights to be enforced. The debate around “second-best decisions” (*orientations par défaut*) perfectly illustrates these dilemmas. This takes place in the context of applications to institutions and services. The “second-best decisions” debate refers to the fact that CDAPH members often make their decisions knowing that the best solution for the applicant currently is not available in the department (for example, sheltered employment the best solution for a young adult currently in a medical-institutional institute, but there are currently no positions available in the department institutes, and the waiting lists are already very long). They therefore find themselves in a position to allocate a right knowing that this right cannot be enforced. The dilemma they are faced with is either to make their decision only according to the applicant’s needs, but knowing that their decision cannot be enforced, or to make their decisions taking into account the constraint of available means, which leads them to decide in favor of a “second-best” solution. While the refusal of “second-best solutions” often is presented as one of the hallmarks of associations representation in CDAPH (and notably, an orientation that would differentiate the position of volunteers from that of professional managers of institutions and services), association representatives in fact are quite ambivalent about this when they comment about this dilemma in the interviews. Their awareness of the local situation is such that they don’t necessarily try to make a point that a decision closer to the applicant’s need would be best to the applicant. A more commonly found argument against “second-best decisions” is the idea that deciding only based on the applicant’s needs, even though it is not necessarily in the applicant’s best interest (since the decision might be impossible to implement, as opposed to a second-best decision), helps shed light on the lack of local resources, and can be used as a leverage to lobby in favor of the creation of new structures or services in the department. Finally, a solution that is commonly used in several departments is the use of “double-decisions” (doubles notifications), that is, decisions that include two options, with the one that suits best the applicant’s needs listed first, and then the “second-best” solution that has more chances to be implemented. However, this common

solution of the “double decision” also is subject to criticism on the part of some organization leaders who point that institution and service managers may be less prone to implement the first solution if they see that a second-best is listed. Therefore, this issue remains a point of controversy among association representatives, a controversy which reveals the very concrete difficulties faced by rights advocates when advocacy takes into account the variable anticipated effectiveness of the rights that are thereby allocated.

While functioning as a place for advocacy, the CDAPH also is a site where “social movement disunity” may be revealed (Barnartt & Scotch, 2001 : 111). Association representatives broadly share a common, implicit conception of representation according to which their role should not be impairment-specific: each of them represents disability at large and should take part in the discussion on all the application, no matter what type of impairment is involved. At the same time, associations are in fact for the most part impairment-specific, and their nomination as CDAPH members follows a criterion of representativeness of the different kinds of disabilities. Association representatives generally bridge the hiatus between the ideal conception of a universalist representation and the reality of impairment-specific organizations by defending the idea according to which they are “interested” in all cases, yet tend to intervene more on the applications that deal with “their” disability, given their impairment-specific expertise. However, in some instances on the discussion of specific cases, conflicts of interests between impairment-specific organizations appear. This is for example the case when a broadening of entitlement to a given right is perceived as diminishing the chances of effectiveness of the right at stake for each constituency. In the following excerpt, a member of a mobility-impairment association criticizes the CDAPH’s tendency to grant parking card to people “who walk”, implicitly because if too many people are entitled to disabled parking spots, the spots will get harder to access for each of them, and notably for people in wheelchairs, who, according to him, need them the most:

*And then, sitting at the rights and autonomy committee also means asserting a particular vision in front of our local authorities. The CDAPH can be, in relation with individual applications that we defend, we can actually convey certain values of our organization. So, take for example, parking cards. [...] it is true that parking cards can be issued – and we are very, very careful about that – can even be issued to people who walk. I mean, there isn’t much monitoring on the parking cards because they are easy to issue and they don’t cost anything. So, since it doesn’t cost any money, they pay less attention to the delivering of parking cards. We have often voiced this preoccupation, this issue [in front of the CDAPH], saying: “No, we must be careful. It is really for people who have trouble walking”.*

The potential exposure of social movement disunity in front of representatives of public authorities helps understand one of the functions of another type of movement implication in the CDAPH, the mobilization around the committee’s norms of functioning. Indeed, this type of mobilization, which will be the subject of the next section, helps recreate a form of movement unity, as opposed to the specialized nature of the expertise mobilized in the discussions of individual applications, as well as the potential conflicts of interests that can emerge throughout these discussions. However, as we will see, the main rationale behind this type of mobilization around the CDAPH’s norms of functioning is the constraint of the

number of files, interiorized by disability organizations, which leads them to re-define their role in terms of scrutiny and control over MDPH decisions, short of being able to actually take part in the decision-making process on each individual application.

### **From decision-maker to watchdog: Rights advocacy through a mobilization around the committee's inner workings**

Beyond the analysis of the way associations representatives position themselves in the CDAPH's discussions on the individual applications, the meaning of associations presence in the committee must be analyzed in light of the CDAPH's actual working, which departs from its legal definition. While according to its constitutive decree<sup>17</sup>, the CDAPH is the MDPH's final decision-maker (each individual application is supposed to be subject to a decision by the committee), MDPH practices significantly depart from these this requirement, with institutional practices varying significantly from one department to the other, as well as in time : in 3 of the 4 departments under study, reforms regarding the CDAPH's norms of functioning were being discussed, and occasioned significant mobilization on the part of civil society organizations. The institutional adjustments at stake are interesting to study both in terms of identifying the way movement advocacy shifts from participation in decision-making to a mobilization around procedures, and in terms of analyzing the dilemmas of intra-institutional advocacy for disability rights advocates.

In practice, even though each decision officially is the committee's, the latter only examines a very small number of individual files. Indeed, the creation of the MDPH in 2006 quickly led to the shared conclusion that the CDAPH could not examine all individual files because of the number of applications to be processed. Each local MDPH designed various institutional arrangements in order to diminish the number of application actually presented to the CDAPH. This reduction of the role of the CDAPH was not, from the point of view of the MDPH, a problem in terms of decision-making since decisions are actually prepared, before the CDAPH, by multi-disciplinary technical teams (Perrier 2012). A certain number of these decisions then happen to be validated without being discussed by the CDAPH. Procedures designed to limit the number of files discussed by the CDAPH include the creation of "sub-committees" (*commissions restreintes*) which include a limited number of committee members, and more importantly, a system of "list-decision" (*décision sur liste*), also labeled "blocked list" in some departments, according to which a certain number of decisions by the technical teams are validated without being discussed by the CDAPH; in this case, the CDAPH's decision-making role is materialized by the simple presence, when the committee meets, of one or a few paper copies of a long list of individual decisions (cf table 1).

#### **"Simple examination" and "in-depth examination" of individual applications by a local committee (CDAPH)**

In one of the departments studied, the CDAPH takes place twice a month over the course of a half-day (9h30-12h30). Unlike other departments, this department does not distinguish between "adults" and "children" CDAPH, a distinction that was inherited from the previous

<sup>17</sup> Décret n° 2005-1589 du 19 décembre 2005

institutional system that was in place in France at the level of departments (CDES for children, COTOREP for adults) from 1975 to 2005. The MDPH teams select a few number of files that they wish the CDAPH to discuss based on specific themes that they want to tackle (for example, schooling, or the issue of young adults being stuck in children's institutions because of the lack of available positions in adult structures). During a CDAPH meeting I observed in June, 2012, 6 applications were discussed during the session. The rest of the decisions made by the technical teams on all of the other applications is validated by the presence, on the table, of a few paper copies of a listing taking the form of a table including the following items:

File number	Name	Date of birth	Contact info	Impairment level (%)	Claim	Technical team proposal	Rights entitlement begins (date)	Rights entitlement ends (date)

Another (one-page) table being circulated during the meeting, entitled "meeting agenda", mentions the total number of decisions validated by the holding of the meeting (604)

	Children	Adults
In-depth examination	3	3
Simple examination	183 (215 applications)	415 (1230 applications)
Total	186	418
	604 files	

The 604 files, here labeled as being subject to a "simple exam", were not mentioned during the discussions. The meeting started with a general discussion of a local disability services issue, which lasted for over an hour, and then 6 individual applications were orally presented, and the discussion around these lasted an hour and thirty minutes.

What do civil society organizations think of such devices, which concretely result in bypassing their decision-making power? While protest would be expected in such circumstances, associations generally accept the principle of a need for such devices. The explanation of their acceptance is twofold. First, most of them are not ready to spend more time for the committee: voluntary organization leaders complain a lot about the time-consuming character of all their "representation" tasks (being on various committees at several levels of government, and the CDAPH is only one of them). In the one out of the four departments we studied where the CDAPH lasted for the longest time (the committee sat from 9 AM to 6 PM), association representatives complained about how exhausted they were at the end of the day:

*I am there all day long. Passed about 4 PM... [He sighs, miming exhaustion]. Because you know, we only have 45 minutes for lunch.*

One of the aspects of working inside the institution is the incorporation of institutional constraints – time constraints in the present case. Association members generally are not willing to spend more time in committee meetings, so increasing committee hours in order to discuss more applications is not an option. Secondly, and in this context in which increasing

committee hours is not an option, association members worry that putting a larger number of files into the discussion process will result in increasing already excessive file-processing delays at the detriment of users in need of quick decisions. Here again, disability rights advocacy faces contradictions in the context of local implementation, when users' right to an administrative decision within a reasonable time is perceived by rights advocates as going against their right to a decision involving representatives of the disability rights movement.

Hence associations generally accept the principle of a need for such devices that reduce their actual participation in the decision-making process. Yet they need to make sense of their participation in the committee as disability rights advocates. As a consequence, they are inclined to redefine their role in the committee, from an actual decision-making role to a role of scrutiny and control of MDPH decisions. Derisory though it may seem, the hundred-pages listing set on the table for CDAPH members to look at symbolizes this "watchdog" role assumed by association members. In the department whose CDAPH was described in the frame above, one of our interviewees mentions this stack of paper, alluding to the possibility of checking, even though it seems hard to do in practice:

*The thing is, when the CDAPH meets, we only see the applications that raised some issues within the technical team. It means that there are about 600 files each week that we don't see. We see between 6 and 8 applications during each session. What I'm saying is, out of the 600 that are processed without us because the technical team didn't have any issue with them, that's where (then, I don't know how we could do that), but that, maybe, is where we should have... How could I put it? You know, there is this stack laying there, each Thursday morning, when we go there, a stack with 600 applications, adults and children altogether, and we should, I don't know, we should arrive there at 5 in the morning [laughs] to see. Because in fact, they only write down "yes" or "no", if an adult disability benefit is allocated, yes or no. If a benefit was not granted, we don't know why. What we should do is say, for example, at the beginning of each CDAPH: "ok, let's randomly..."*

Q: Yes, "this file, let's check"

A: Yes, that's it.

Q: Do you have the right to ask to look at a given file?

A: Yes, to ask that it be examined [by the CDAPH]. Well, then... We figure, we trust the technical team. I mean, they are professionals. They are people like you and me, we'll say, doing their job.

The idea, in this perspective, is to avoid that the committee become a mere "rubber-stamping" assembly, according to an expression which often comes up in the interviews (here, in another department):

*[Referring to a recent MDPH proposal to increase the number of files that would be processed through the "blocked list" system] What I'm saying is, we shouldn't let things like that happen; otherwise what's the use of us going to the CDAPH? They are taking away all the point of civil society organizations being in this committee. If we don't see the decisions anymore – even for children – I'm missing something here. If everything*

*goes directly through, what's the point of us being there? Then we're a mere rubber-stamp. Period.*

In order to avoid this situation in which the commission becomes a mere “rubber-stamp”, associations generally try to keep control, or at least show they have some influence, over the definition of the criteria used to enable an application to be processed through the “blocked list” procedure.

However, this mobilization is not always free from ambiguities, in so far as it does not question the general assumption according to which the number of applications presented in front of the CDAPH must be reduced. This leads to surprising scenes, such as one I witnessed in one of the departments where CDAPH members were holding a meeting in order to define new procedures for the committee. At the beginning of this session, a representative of the MDPH introduces the criteria that were adopted at the previous meeting, defining applications that had to be examined by the CDAPH. While projecting a slide with the list on a screen, the MDPH representative orally notes that it was decided during the previous session that the number of applications being discussed would be limited to “8 to 15 files per session”, and that given the fact that the CDAPH meets half a day per week, “we will not be able to examine all the files that match these criteria. We trust the [technical] team to select the 15 files”. One of the association representatives, who had missed the first session, asks questions about several of the criteria, and insists on adding two new criteria (Refusal of recognition as a disabled worker (RQTH) and training refusal) to the list following which the MDPH representative directly modifies the slide to add the new criteria. However, association representatives don't make any comments regarding the statement according to which the number of applications being discussed would be limited to “8 to 15 files per session”<sup>18</sup>. While the introduction of such a limit would seem to make the whole mobilization around the precise definition of the criteria irrelevant, this mobilization makes sense for the organizations as a way to assert their role as watchdogs<sup>19</sup>.

Further, mobilizing against planned reforms of CDAPH functioning also helps create social movement unity, against the previously described tendency to segmentation. The following excerpt is particularly significant in this perspective: in another department, I ask the president of an organization about whether he perceived a clear split, within the CDAPH,

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<sup>18</sup> To be sure, since this was the second day of a meeting devoted to the reform of CDAPH functioning, this may have been a point of discussion during the previous session. However, nobody contradicts or expresses dissatisfaction facing the statement, when other criticisms are expressed (regarding the definition of the criteria). This tends to validate the idea of a consensus regarding the limitation of the number of files being discussed.

<sup>19</sup> The possibility of an effect of my presence cannot be completely neglected either. The presence of an outside observer, especially since I had mentioned being in charge of the disability rights organization section of the collective project, may have influenced to some extent the behavior of association members. A scene observed during another CDAPH discussion on individual applications, involving the same CDAPH members, suggested that the role played by this association representative may have been to some extent influenced by my presence: in a discussion on allocation of school aid to a child, this same association representative stressed the fact that the number of hours of aid allotted per week should be specified on the notification, otherwise “It doesn't really create entitlement. If we don't specify a minimum amount of time, the school may say “no more than two hours””. Then he looked at me and said “The associative is speaking here”. The observer's paradox however here reveals what association representatives conceive as the role they should be playing (defending a child's right to proper school aid), and is significant if analyzed as such.



between association representatives and other representatives. While asking this question, I had in mind possible diverging opinions on individual applications, whereas he immediately answered mentioning the current mobilization around a planned reform of CDAPH functioning as a factor of movement unity:

*Q: Regarding the positioning of the different members within the CDAPH, are there recurring dividing lines that appear? For example, are associations always on the same position as opposed to...?*

*R: We have a consistence among associations and we try to remain this way. Notably, I know that I... Here, we've been working on [...] blocked lists. Block lists are against the law since, theoretically, applications are not supposed to be processed through blocked lists. Alright. But then we must recognize that we don't have the choice because otherwise we would have to sit at the committee every day; since about 60% of the applications are processed through the blocked list system. [But now] they want to be able to process more applications through [this system], notably in the children's department, they wanted to have everything go through blocked list except when parents appeal and when the technical team had specific issues with a file. [...] We, the associations, we said "No, no way". We did not agree. So regarding this, I immediately phoned all the associations that sit at the CDAPH, by means of [a local cross-disability coordination of associations], so we could have a meeting and define a position.*

Here, the immediate evocation of the mobilizations around the CDAPH's functioning reveals the importance of this issue for disability rights organizations. While adjusting to institutional constraints through their acceptance of the need to limit the number of files being discussed, association representatives still want to preserve a distinct advocacy stance within the Committee, by means of the establishment of a form of a right of oversight over MDPH decisions. Collective mobilization around the preservation of this right of oversight helps create a form of social movement unity, which otherwise is not obvious in the process of discussing the individual applications.

## **Conclusion**

The courses of action taken by disability rights organization members and professionals within and around the "rights and autonomy committee" reveal and help specify some of the tensions inherent to social movements endorsing an institutional role.

The study of pre-application counseling practices reveals a clear partition between volunteers and professionals (the latter systematically helping applicants, following a management logic, and the former often expressing reluctance to institutionalize this role as a volunteer role within their organizations), as well as intra-movement differences regarding voluntary involvement in counseling. Being on the allocation committees, association leaders come to interiorize some of the institutional constraints, such as the idea of a limited available time and the need to reduce delays in file processing. The need to do with institutional constraints does not, however, lead to association members taking on a purely institutional role, but

favors a reframing of advocacy, in terms of oversight rather than participation in decision-making.

Moreover, intra-movement differences appear at all stages of disability organizations' involvement; more contentious stances have been noticed on the part of organization members who themselves are disabled (which, in France, corresponds for the most part to mobility-impairment organizations as well as hearing-impairment and visual impairment organizations). This, however, is not systematic, which suggests that the way association members define their role in CDAPH is a complex result of their social background, political socialization, the guidelines provided by the disability organization they are part of, as well as the interactions which take place among committee members.

Finally, the study of this particular form of advocacy at the local level illustrates the influence of the movement's embeddedness in a local setting on the definition of advocacy: information such as knowing who the right doctors are, or knowing how long the waiting list is for a given service or facility, undeniably influence the forms taken by this discreet type of advocacy through participation in the allocation of rights.

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